# Measuring and Strengthening Patient Participation

*A research foundation and evaluation agenda for The Patient Better Project*

The Patient Better Project

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## Abstract

How can healthcare professionals strengthen the patient's role in care when they lack a clear way to assess the patient's ability to participate? Providers need to understand what patients can do and where patients need education or support. This paper examines what participation requires and where existing support falls short. The discussion distinguishes practical participation from health literacy, activation, and engagement to clarify what assessing patient participation as its own category can reveal.

The Patient Better Project Inc. has developed assessment tools to document patients' reported participation skills and practices alongside circumstances that affect their ability to participate. These assessments provide a starting point for identifying support needs and studying changes over time. Providers and researchers can use the assessment framework to evaluate different educational approaches.

The paper examines the evidence needed to establish reliable measurement and determine whether education strengthens participation. The proposed research asks which activities matter most and whether changes in participation affect care, communication, healthcare use, and patient experience. The goal is to give healthcare professionals a dependable way to identify participation needs, guide support, and evaluate progress.

## 1 Purpose and evidence

The purpose of assessing patient participation is to identify what patients need help doing and determine whether that help makes a difference. Providers need evidence about patients' preparation, communication, organization, and follow-through to select appropriate support. Researchers need dependable measurements to establish which approaches improve participation and whether those improvements affect care.

Published trials provide a reason to pursue this work. In a 1988 randomized trial involving 59 patients with diabetes, Greenfield and colleagues tested a 20-minute session in which a clinic assistant helped patients review their medical information and prepare to discuss care with their physician. Patients who received the intervention obtained more information from their physicians and showed improved blood sugar control. The study demonstrated that teaching patients how to participate could change both their behavior during appointments and a clinical outcome. PubMed

Grant and colleagues examined appointment preparation in a 2019 randomized trial involving 750 primary care patients. At baseline, fewer than half of participating physicians reported that patients usually or always arrived prepared with their main concerns. Patients who used the study's Visit Planner reported better preparation and were more likely to communicate their priorities at the beginning of the appointment. However, the intervention did not produce greater improvement in clinical care gaps over six months. These findings show

why researchers must measure participation and care outcomes separately: better preparation does not automatically produce better clinical results. PMC

Evidence also extends beyond the appointment. In a 2006 randomized trial involving 750 adults aged 65 or older, Coleman and colleagues tested a program that combined a transition coach with tools and support for managing care after hospitalization. Patients receiving the intervention had lower rehospitalization rates at 30 and 90 days. Because the program combined several forms of assistance, the findings support the overall intervention without establishing which participation activities produced the benefit. JAMA Network

Researchers have also developed instruments to assess participation. The Patient Preferences for Patient Participation tool, known as the 4Ps, compares how patients want to participate with how they experience participation. That comparison addresses a different question from whether patients have the practical skills and support to carry out care responsibilities. The distinction explains why providers need to understand exactly what an assessment measures before using the results to guide support. pmc.ncbi.nlm.nih.gov

Together, these studies support investigating participation as something that can be taught, assessed, and connected to outcomes. The remaining task is to determine which activities matter, who needs assistance, and how providers can reliably recognize progress. The Patient Better Project Inc.'s Healthcare Proficiency Challenge and Readiness Assessment provide a proposed approach to that task. Direct studies of these tools are needed to establish the accuracy and consistency of their results and whether providers can use those results to improve support.

## 2 What patient participation means

Researchers have historically described patient participation through the relationship between patients and healthcare professionals. Definitions have included sharing information, taking part in decisions, and working together on care activities. In their 2008 concept analysis, Sahlsten and colleagues identified these features alongside professionals' willingness to share control. Their definition recognized participation as an interaction that both patients and professionals help make possible. pubmed.ncbi.nlm.nih.gov

Other researchers have examined whether patients participate in the ways they want. The Patient Preferences for Patient Participation instrument, known as the 4Ps, compares patients' preferences with their reported experiences. This approach helps identify whether patients receive opportunities for involvement that match their preferences. However, a match between preferences and experiences does not establish whether a patient can organize medical information, prepare for an appointment, or carry out follow-up responsibilities. Those abilities require direct attention. pmc.ncbi.nlm.nih.gov

Researchers have also demonstrated practical approaches to strengthening participation. Greenfield and colleagues taught patients to review medical information and obtain information from their physicians. Grant and colleagues helped patients prepare and communicate their priorities for an appointment. These trials established that researchers can identify specific participation activities and measure changes following an intervention. The challenge is to connect such activities within a clear framework that providers can use to assess needs across appointments and daily life. pubmed.ncbi.nlm.nih.gov

The Patient Better Project Inc. advances this practical emphasis to address healthcare quality improvement needs:

**Patient participation is the practical work patients undertake, independently or with assistance, to prepare for care, communicate relevant information, organize their health information, coordinate care activities, and follow through on care plans before, during, and between appointments.**

This definition gives providers specific activities to assess and strengthen. Preparation includes gathering information and identifying concerns. Communication includes describing symptoms, asking for clarification, and reporting difficulties. Organization includes maintaining usable medication lists and care records. Coordination and follow-through include arranging next steps, carrying out agreed instructions, and informing the care team when circumstances interfere.

Practical participation belongs in its own assessment category because providers need to know which of these activities patients can carry out and where support is missing. Health literacy, activation, and engagement help explain participation but do not make every practical task visible. For example, the Patient Activation Measure addresses knowledge, skills, confidence, and action in managing health. A practical participation assessment asks more specifically which care responsibilities a patient can manage and which require education or assistance. Researchers must examine how much useful information that distinction adds to existing measures. pmc.ncbi.nlm.nih.gov

The Patient Better Project Inc. connects this definition to the Healthcare Proficiency Challenge and Readiness Assessment. The Healthcare Proficiency Challenge documents reported skills and practices. The Readiness Assessment records circumstances that may affect participation. Providers can use that starting point to identify support needs. Researchers can evaluate changes after education or other assistance and investigate whether those changes affect care.

The purpose of the category is to make patients' practical contributions clear enough to document, teach, and evaluate. Providers retain responsibility for clinical care and clear instructions. Patients may participate with assistance, and reporting an obstacle is itself a useful contribution. Assessment should reveal what support is needed so that participation becomes a practical part of quality improvement.

## 3 What patients are expected to do

A patient arrives to their appointment with a current medication list, notes about recent symptoms, and questions for the provider. During the appointment, the patient explains what has changed since their last appointment and discusses any difficulty carrying out the proposed plan. The patient leaves with clear next steps and knows how to report progress or ask for help if necessary. This is what practical patient participation can look like when patients have the preparation and support to carry out their responsibilities.

For healthcare professionals, the value is concrete. Providers can review information patients have prepared, address concerns earlier, and identify obstacles before patients leave. Between appointments, patients can supply information that helps the care team understand whether a plan is working. These contributions give professionals a stronger basis for delivering care.

Patients need to learn what these responsibilities involve. A request to "come prepared" gives little direction to someone who has never learned how to organize medical information. Instructions to "follow up" may leave a patient unsure about whom to contact or what to arrange. Providers need to make each activity clear and determine whether the patient can complete the activity independently or needs assistance.

The following sequence connects patient responsibilities with their purpose and the professional support needed to carry them out.

| Stage of care | What patients need to do, with assistance when needed | Why that activity matters | How professionals support participation |
|---|---|---|---|
| Before the appointment | Gather medication information, record recent changes, and write down concerns. | Give the care team information needed to understand the patient's situation. | Explain what to bring and help patients prepare. |
| At check-in | Confirm contact information and explain communication or assistance needs. | Help staff reach the patient and arrange needed support. | Provide understandable forms and respond to identified needs. |
| During intake | Review current medications and describe symptoms or changes since the last visit. | Help the care team work from accurate, current information. | Check details and resolve missing or conflicting information. |
| During the consultation | Explain concerns, ask questions, and discuss whether the proposed plan can be carried out. | Help the provider develop a plan the patient understands and can put into practice. | Explain options, check understanding, and address practical obstacles. |
| Before leaving | Record next steps and confirm follow-up arrangements and whom to contact with questions. | Help the patient leave knowing what to do next. | Provide clear instructions and confirm responsibilities for follow-up. |
| Between appointments | Carry out agreed steps, track relevant changes, and report difficulties or unresolved needs. | Help the care team evaluate progress and respond when the plan needs adjustment. | Provide a clear contact route and respond to reported concerns. |

Each stage prepares the patient and care team for the next. Information gathered at home supports the discussion during the appointment. That discussion leads to a plan with clear responsibilities. The patient's account of progress and difficulties then informs the next care decision. Participation provides continuity across those steps.

Quality participation also makes problems visible. A patient who reports being unable to obtain a medication gives the provider an opportunity to address the obstacle. A patient who asks for an explanation reveals a need that might otherwise remain unnoticed. A caregiver who helps maintain records can support participation when the patient cannot manage that task alone. Providers need to recognize these contributions when assessing how patients participate.

The Healthcare Proficiency Challenge and Readiness Assessment provide a starting point for identifying reported skills, practices, and circumstances that affect these responsibilities. Providers can then clarify specific needs and select education or assistance. Reassessment can help researchers and providers examine whether patients' participation changes after that support.

The aim is for healthcare professionals to know what patients are prepared to contribute and where help is needed. Patients gain clear responsibilities and the means to carry them out. Providers gain a documented basis for supporting those contributions and studying their effect on care.

## 4 Where existing support falls short

Before expecting patients to participate in their care, providers need a baseline understanding of patients' participation skills and support needs. Asking patients about their goals and explaining treatment options does not tell providers whether patients can prepare medical information, organize instructions, or arrange follow-up

care. Without assessing those abilities, providers may leave patients with responsibilities they need help carrying out.

Researchers have recognized this gap. In a 2013 analysis, Bernabeo and Holmboe identified insufficient attention to the skills patients and professionals need for effective engagement and shared decision-making. They called for education and support alongside changes in how practices deliver care. Their analysis establishes that meaningful participation requires preparation from patients, professionals, and healthcare organizations. www.healthaffairs.org

Patient Better addresses this gap through patient-prepared care. Principle 2 of the guiding principles establishes that patients need to learn how to participate before professionals expect effective participation. Providers can respect patients' goals while assessing whether patients have the skills to act on those goals. A patient who wants better diabetes control, for example, may need help recording relevant information and preparing that information for review. The goal identifies what matters to the patient. Assessment identifies the practical support needed.

Providers also need to distinguish clinical education from participation education. Explaining a condition or treatment serves a different purpose from teaching someone to maintain a medication list, organize care records, or prepare for appointments. Principles 6 and 8 address this distinction by giving navigation education a defined place in patient preparation. Patients need instruction in the practical activities that help them use clinical guidance across appointments and daily life.

Delivering that instruction is only part of the work. Providers need to check whether patients understand the instructions and can apply them. The Agency for Healthcare Research and Quality recommends teach-back to check understanding by asking patients to explain information in their own words. Patient Better's Principle 3 extends the focus to practical behavior: providers need evidence of how patients carry out participation activities. A patient explaining why a medication list matters and a patient maintaining an accurate list demonstrate different abilities. www.ahrq.gov

Providers must also distinguish a learning need from a circumstance that education alone cannot resolve. A patient may understand how to arrange follow-up care but lack transportation. Another patient may need assistance reading instructions or organizing several providers' recommendations. Principle 7 directs attention to each patient's participation capacity. Principle 10 calls for educational methods suited to the learner. These principles connect the identified need to an appropriate response rather than assuming the same instruction will help every patient.

The Patient Better Project Inc. advances this approach by connecting practical participation with a documented assessment process. The Healthcare Proficiency Challenge records reported skills and practices. The Readiness Assessment adds circumstances that may affect the patient's ability to participate. Providers can review those findings, clarify the specific difficulty, and select education or assistance. Providers and researchers can then reassess participation to examine what changed.

This contribution gives providers a defined way to move from expecting participation to identifying and supporting the abilities participation requires. The assessment framework connects the patient's starting point with support and subsequent evaluation. Research must now establish how dependably the tools identify needs and whether using the findings improves participation and care.

# 5 How participation relates to established concepts

Patient participation connects patient education, health literacy, activation, and engagement through the practical activities of care. Patients draw on what they understand, what they have learned, and the support available to them when preparing for appointments or following a care plan. The Patient Better Project Inc. brings those activities together so providers can identify specific participation needs and select appropriate support.

Each established concept helps explain a different part of that process.

| Concept | What the concept addresses | Connection to practical participation |
|---|---|---|
| Patient education | Teaching knowledge and skills needed for health and care. | Patients learn how to prepare information, communicate concerns, and carry out care responsibilities. |
| Health literacy | Finding, understanding, and using health information and services, with support from healthcare organizations. | Patients use information to understand instructions, navigate services, and determine next steps. |
| Patient activation | Knowledge, skills, confidence, and action in managing health. | Patients draw on these abilities when taking an active role and sustaining participation. |
| Patient engagement | Involvement in direct care and in the design and governance of healthcare services. | Patients and professionals have opportunities to work together on care. |
| Practical patient participation | Preparing, communicating, organizing information, coordinating care, and following through. | Providers examine which activities patients carry out and where education or assistance is needed. |

These concepts overlap. Healthy People 2030 recognizes both individuals' ability to use health information and organizations' responsibility to make information and services accessible. Hibbard and colleagues' activation research includes action alongside knowledge and confidence. Carman and colleagues' engagement framework extends from individual care to organizational decisions and policy. Practical participation brings the focus to the activities a patient needs to carry out within that broader context. odphp.health.gov

Researchers have already developed tools that help providers assess relevant abilities. Those tools measure different aspects of literacy and activation, so providers need to understand what each result can tell them.

| Instrument | What the instrument assesses | What providers can learn |
|---|---|---|
| Rapid Estimate of Adult Literacy in Medicine (REALM) | Recognition and pronunciation of medical words as an estimate of reading ability. | Whether a patient may need assistance with written health materials. |
| Test of Functional Health Literacy in Adults (TOFHLA) | Reading comprehension and numerical skills using healthcare materials. | Whether a patient has difficulty interpreting written or numerical health information. |
| Health Literacy Questionnaire (HLQ) | Nine areas including understanding information, navigating services, interacting with professionals, and receiving support. | A profile of health literacy strengths and needs. |
| Patient Activation Measure (PAM) | Reported knowledge, skills, and confidence for managing health, including taking and sustaining action. | The patient's level of activation and potential needs for self-management support. |

Davis and colleagues validated the shortened REALM against established reading tests. Parker and colleagues developed TOFHLA around reading and numerical tasks encountered in healthcare. Osborne and colleagues developed the HLQ to capture a broader range of health literacy needs. Hibbard and colleagues developed and tested PAM to assess activation. These instruments demonstrate that providers have alternatives to assuming patients' abilities, although no single result answers every practical participation question. pubmed.ncbi.nlm.nih.gov

The remaining issue is how providers connect assessment results to everyday care responsibilities. A reading score does not establish whether a patient maintains a current medication list. An activation score does not verify whether a patient completed a referral. Broader measures such as the HLQ already address navigation and interaction with professionals. The Patient Better Project Inc.'s contribution therefore needs to be evaluated for the specific information and support decisions its activity-focused approach adds.

The Healthcare Proficiency Challenge and Readiness Assessment are designed to make that connection more explicit. Providers can review reported practices alongside circumstances that affect participation, then clarify the activity that needs attention. A patient's report provides information that can be discussed and documented. When needed, providers or researchers can also ask the patient to demonstrate a task. This process reduces reliance on assumptions while distinguishing reported ability from demonstrated performance.

The same distinction matters when selecting education. Rote learning emphasizes remembering information. Meaningful learning includes understanding information well enough to apply learning to another situation. Mayer's work distinguishes retention from transfer and explains why educational assessment should examine more than recall. www.tandfonline.com

For example, a patient may remember being told to bring a medication list. Applying that instruction requires the patient to create the list, update changes, and make the information available at the next appointment. Participation education should include explanation, practice, and opportunities to apply the skill. Researchers should then examine whether patients can use the skill beyond the lesson.

Peer review and evidence address how well research supports an assessment or educational approach. Peer review subjects a study to expert scrutiny. Evidence comes from the study's methods and findings. For The Patient Better Project Inc., researchers need to answer two separate questions: **Does the education work? Does the assessment measure participation accurately and consistently?**

To evaluate education, researchers need to test whether patients can use what they learn in their actual care. Teaching patients how to organize a medication list is the educational approach. Checking whether patients can create and maintain an accurate list shows whether that approach worked.

To evaluate measurement, researchers need to study the assessments themselves. Research supporting PAM, REALM, or TOFHLA supports those particular tools. The Patient Better Project Inc. can build on that research, but the Healthcare Proficiency Challenge and Readiness Assessment need their own studies to establish the accuracy and consistency of their results. Researchers can evaluate these assessments alongside different educational approaches.

The Patient Better Project Inc. establishes practical patient participation as an explicit category for assessment, documentation, and reporting. Providers need to identify participation needs, record a baseline, select an intervention, and measure change. Patient Better LLC provides an educational intervention, and providers may use other approaches within the assessment framework. Follow-up tools, including the Completion Survey, can

document patients' reported learning and changes in participation. Section 6 explains how these assessments support measurement and reporting and what evidence is needed to establish dependable results.

# 6 Can patient participation be reliably measured

Patient participation can be assessed, documented, and reported through defined activities and consistent assessment procedures. Providers need to know what patients report doing, which responsibilities require assistance, and whether participation changes after support. Reliable measurement requires evidence that the assessments produce consistent results under comparable conditions and that providers can interpret those results accurately.

The Patient Better Project Inc. has developed a framework that connects an initial assessment with intervention and follow-up. The Healthcare Proficiency Challenge records reported participation skills and practices. The Readiness Assessment identifies circumstances affecting participation. The Completion Survey documents reported learning and change after education. Each tool contributes different information to the measurement process.

### Measurement connects patient abilities to care responsibilities

Providers need to understand whether patients are prepared to carry out the responsibilities of a proposed care plan. A plan may require patients to track symptoms, use a monitoring device, communicate through a portal, coordinate appointments, or follow detailed recovery instructions. Assessing these activities makes the support needed to carry out the plan more visible.

The assessment process begins with identifying what the care plan requires. Providers then examine the patient's reported abilities and circumstances. When a particular responsibility requires confirmation, providers can ask the patient to demonstrate the task or explain the next steps. For example, a patient preparing to use a home monitoring device may need to demonstrate how to take a reading and explain when and how to contact the care team.

Researchers can connect participation findings with the procedure or service being studied. A procedure code identifies the service, but the care team must specify the patient activities associated with that service. Studies can then examine whether participation abilities and support relate to follow-through and outcomes. Predicting outcomes for a particular procedure requires evidence from patients receiving that care.

The purpose is to identify preparation and support needs early enough to address them. A participation assessment should help providers determine whether education, caregiver assistance, or another arrangement would help the patient carry out the plan.

### The Healthcare Proficiency Challenge establishes the initial profile

The Healthcare Proficiency Challenge contains ten questions about practical participation. The questions address record retrieval, sharing health information, preparing for appointments, portal access, note-taking, understanding healthcare terminology and insurance, and maintaining an organizational system. Patients select yes, no, or an item-specific alternative response.

The current scoring places affirmative responses into four bands: 0–2, 3–4, 5–6, and 7–10. Providers can document individual responses and the resulting band as the patient's initial assessment profile. Individual answers help providers identify the activity that needs clarification or support.

These responses describe what patients report knowing or doing. Providers should record a demonstrated task separately from a patient's self-report. For example, reporting the ability to retrieve a medical record and successfully retrieving a requested record provide related but different evidence.

The four bands provide an existing classification structure for research. Studies need to establish whether the bands identify meaningful differences in participation needs and whether a total score supports useful decisions. The proportion of affirmative answers should not be interpreted as a validated percentage of overall participation ability.

### The Readiness Assessment identifies circumstances affecting participation

The Readiness Assessment adds information about responsibilities, communication access, devices, education, language, and living circumstances. Providers use these responses to understand what may affect the patient's ability to participate and which forms of support are feasible.

The Healthcare Proficiency Challenge and Readiness Assessment answer complementary questions: what does the patient report being able to do, and what circumstances affect the patient's ability to carry out those activities? Providers need both kinds of information when selecting support. A patient who lacks internet access may need a different communication method. A patient who does not know how to organize records may need instruction and practice.

Providers review the findings, clarify uncertain responses, and document the support selected. The assessment replaces an unsupported impression with information that can be examined and revisited. Professional judgment remains necessary to interpret that information in relation to the patient's care.

Readiness responses should remain distinguishable from participation scores. A practical obstacle does not automatically indicate low skill or low motivation. Likewise, an Empowerment form can document a decision about participation or support, but a signature does not establish proficiency or understanding.

### The intervention remains separate from the measurement

The Patient Better Project Inc. develops and licenses the assessment tools. Patient Better LLC provides the Academy as an educational intervention. Providers may instead use their own education or another appropriate form of support.

This separation allows researchers to study different interventions within the same assessment framework. Providers identify the need first and then select a response. Academy enrollment is not required to establish a baseline, and course completion alone does not demonstrate effective participation.

Researchers must describe the intervention clearly enough to understand what patients received. Relevant details include the skills taught, delivery method, duration, assistance provided, and opportunities to practice. These details help explain why patients may respond differently to different approaches.

### The Completion Survey documents reported learning and change

The Completion Survey adds follow-up information about patients' reported knowledge, skills, and confidence. The survey contains 18 statements with paired five-point ratings for "Before Course" and "After Course." The statements cover healthcare navigation, financial understanding, information organization, coordination, and communication.

Written questions ask patients what helped, what needs improvement, and how they applied the information to their care. These responses can help providers understand the patient's learning experience and identify remaining support needs.

The ratings and written answers are raw patient-reported data. Providers can document individual responses and examine reported changes. Researchers can analyze patterns across participants while preserving the distinction between perceived improvement and demonstrated performance.

Patients may also understand their starting point differently after education. A patient who previously considered arriving at an appointment sufficient preparation may later recognize the work involved in organizing records and documenting changes. Learning can change both a patient's abilities and the standards the patient uses to judge those abilities. Researchers describe this change in self-evaluation as *response shift*. pubmed.ncbi.nlm.nih.gov

Survey administration needs to account for that possibility. When patients complete the earlier ratings before instruction, providers have a baseline recorded at that time. When patients complete both columns afterward, the earlier ratings represent the patient's remembered starting point viewed through current understanding. This retrospective approach can offer useful insight, but recall and other influences can affect the answers. Researchers should identify the method used and examine its effects on interpretation. pmc.ncbi.nlm.nih.gov

### The Completion Survey can support evaluation of different interventions

Providers can use the Completion Survey to investigate reported learning after their own intervention as well as after Patient Better LLC's Academy. The survey questions must remain relevant to the education being evaluated.

The supplied version names the Patient Better Program and includes specific resources such as the SOAP Note and Treatment Plan Calculator. Researchers evaluating another intervention should document any changes to these references and identify questions that do not apply. A question about an untaught resource should not be scored as evidence that a patient failed to learn the intended material.

Consistent questions and administration procedures support comparison across interventions. Changes in wording or content must be recorded, and researchers must establish whether results from different versions can be compared. This approach preserves flexibility while keeping the meaning of the reported findings clear.

### Reporting makes the assessment process traceable

A participation report should connect the patient's starting point with the support provided and the findings at follow-up.

| Stage | Information to document | What the information tells providers |
|---|---|---|
| Initial assessment | Instrument version, date, item responses, score band, and assistance received. | The patient's reported participation practices and abilities at the starting point. |
| Readiness review | Relevant circumstances, available support, and identified obstacles. | What may affect the patient's ability to carry out care responsibilities. |
| Intervention | Education or assistance delivered, timing, and opportunities to practice. | What support the patient received. |

| Stage | Information to document | What the information tells providers |
|---|---|---|
| Completion Survey | Item ratings, written feedback, and whether earlier ratings were recorded before instruction or recalled afterward. | The patient's reported learning, experience, and remaining difficulties. |
| Practical follow-up | Task demonstrations or documented use of skills during care. | Whether the patient can apply the relevant learning. |

Reports should distinguish a change in survey responses from demonstrated skill improvement and from an improvement attributable to the intervention. Each finding answers a different question. Keeping those findings separate makes the report more useful for care decisions and research.

## Evidence required for measurement claims

The Patient Better Project Inc. has developed tools that produce documentable and reportable responses. Direct studies must establish how consistently and accurately those tools measure participation and how well they detect meaningful change.

Researchers need to answer two separate questions: **Does the assessment measure participation reliably? Does the intervention improve participation?** Evidence supporting one answer does not automatically establish the other.

First, researchers must examine the questions themselves. Patients and caregivers should explain how they interpret each question. Clinicians and measurement specialists should evaluate whether the questions cover the intended activities. Questions that combine several tasks or depend on a particular technology need careful review so that providers can understand what each answer represents.

Second, researchers must test consistency. Patients whose participation has remained stable should complete the same assessment under comparable conditions. Researchers should examine agreement, score reliability where appropriate, and measurement error. When professionals assess demonstrated tasks, researchers should also test whether different observers reach similar conclusions.

Third, researchers must test the meaning of the results. Relevant self-reports can be compared with independently assessed activities such as retrieving a record, preparing a medication list, or explaining follow-up arrangements. Researchers should examine whether the four Healthcare Proficiency Challenge bands identify different support needs and whether individual responses offer more useful guidance than a combined score.

Fourth, researchers must evaluate the Completion Survey's ability to capture learning and change. Studies should distinguish ratings recorded before instruction from ratings recalled afterward. Researchers should compare reported improvement with task demonstrations and subsequent use of skills. A combined survey score requires evidence that combining the questions produces an interpretable measure.

Fifth, researchers must examine whether the tools work fairly across languages, administration methods, and assistance arrangements. Assessments should record when patients lacked an opportunity to perform an activity. Patients who have not needed a referral, for example, should not automatically be treated as unable to coordinate one.

Finally, researchers must determine whether using the findings improves support and care. Studies should examine whether providers identify a specific need, deliver a suitable intervention, and revisit the need afterward. Comparative studies can help separate intervention effects from other explanations for change.

Including patients who decline or do not complete an intervention will help researchers understand where the process succeeds and where additional support is required.

The Patient Better Project Inc. provides a defined structure for assessing, documenting, and reporting practical participation. The Healthcare Proficiency Challenge, Readiness Assessment, and Completion Survey connect reported abilities and circumstances with intervention and follow-up. Validation will establish how dependably providers can use those findings to prepare patients for care responsibilities and evaluate progress.

# 7 Can education strengthen participation

**Education can strengthen patient participation when patients are taught practical skills and given opportunities to use them.** Published studies have demonstrated improvements in preparation, communication, and self-management after structured instruction. The next question is how to build those skills into a foundation patients can use throughout their healthcare journey.

Measurement identifies where patients need help. Education addresses the skills that need development. Follow-up assessment shows whether patients can apply their learning to the responsibilities of care. Providers need all three steps to understand whether an intervention is helping.

## Three educational purposes

Patient Better distinguishes three categories of patient education by their purpose. The distinction helps providers identify what patients need to learn and select an appropriate educational response.

| Educational category | Purpose | Example |
|---|---|---|
| Clinical education | Provide individualized guidance from qualified healthcare professionals about diagnosis, treatment, medications, and care instructions. | A clinician explains a medication change and the symptoms the patient should report. |
| Condition and lifestyle education | Help patients learn about a condition and relevant daily health choices through educational resources and self-directed research. | A patient reads about nutrition or physical activity related to a diagnosis. |
| Healthcare navigation education | Teach patients how to find and evaluate information, prepare for care, organize records, communicate, coordinate services, and follow through. | A patient learns how to maintain a medication list and prepare information for different providers. |

The same health topic may appear in all three categories, but each category serves a distinct educational purpose. A provider's individualized medication instructions guide treatment. An article supplies general information about the medication. Navigation education teaches the patient how to evaluate that article, record questions, and discuss relevant concerns with the provider.

This distinction matters because access to information does not establish the ability to use information appropriately. A patient may find an online claim without knowing who produced the claim, what evidence supports it, or whether the claim applies to the patient's circumstances. Navigation education should teach patients how to examine those questions and bring unresolved concerns to a qualified professional.

## Navigation education provides a foundation across conditions

Patients' participation responsibilities continue as diagnoses, medications, providers, and care settings change. Patients still need to locate records, explain concerns, organize instructions, and coordinate next steps. These recurring responsibilities provide a basis for education that follows the patient across care.

Education organized only around the current diagnosis or product can leave those shared responsibilities unaddressed. Instructions for one medication may help a patient use that medication correctly without teaching how to maintain a complete medication list. A tutorial for one portal may explain where to click without teaching how to identify a missing result or request information from another organization.

Patient Better's approach places these continuing responsibilities at the center of navigation education. Patients learn a general process and then practice applying that process in specific situations. For example, record-retrieval education should address what information is needed, who holds the information, how to request access, and what to do when the first attempt fails.

The goal is to help patients adapt when care changes. An unfamiliar app or portal may still require additional instruction or accessibility support. Foundational education gives patients a process for approaching the task and recognizing when assistance is needed.

## Research supports teaching practical participation skills

Studies across several healthcare settings support the value of preparing patients to participate. The findings also show why researchers must identify the skill taught and measure the outcome that the intervention was intended to change.

| Study | What patients were taught or supported to do | Findings and relevance |
|---|---|---|
| Kinnersley and colleagues, *BMJ*, 2008 | Prepare questions and gather information during consultations through coaching or question prompts. | Across 33 randomized trials involving 8,244 patients, interventions produced small improvements in question asking and satisfaction. The review supports structured preparation for communication. |
| Alegría and colleagues, *JAMA Psychiatry*, 2014 | Identify care decisions, develop questions, and practice discussing needs through the DECIDE intervention. | Patients reported improved activation and self-management. Researchers found no evidence of improved attendance or retention, showing that learning and continued access to care require separate evaluation. |
| Lorig and colleagues, *Medical Care*, 1999 | Develop common self-management skills through a program serving people with several chronic conditions. | The randomized trial of 952 participants reported improvements in communication with physicians and several health measures, alongside fewer hospitalizations and hospital days. The study supports the feasibility of education shared across diagnoses. |
| Coleman and colleagues, *Archives of Internal Medicine*, 2006 | Use care-transition tools and coaching to take a more active role after hospital discharge. | The trial of 750 older adults found lower rehospitalization rates at 30 and 90 days. The findings support a combined education-and-support approach during transitions. |

Kinnersley and colleagues' review demonstrates that patients can receive structured help to ask questions and obtain information. The included trials varied in quality, and improvements were modest. The findings support teaching a defined communication activity without implying that brief preparation improves every aspect of care. PubMed

The DECIDE trial provides an example of active instruction. Patients received three sessions that included explanation, role-play, and reflection. The primary analysis included 647 patients from 13 outpatient mental health clinics. Improvements in reported activation and self-management support teaching patients how to participate in discussions. The absence of an effect on attendance and retention also highlights the continuing importance of access, practical assistance, and professional responsiveness. JAMA Network

Lorig and colleagues' trial is particularly relevant to a common educational foundation. Participants had heart disease, lung disease, stroke, or arthritis and attended a shared self-management program. The findings provide evidence that patients with different diagnoses can benefit from common instruction. That program was broader than navigation education, so the results support the rationale for shared skills without establishing the effectiveness of Patient Better's specific curriculum. PubMed

Coleman and colleagues' care-transition trial connected preparation with support during an actual change in care setting. Patients received tools and coaching rather than instructions alone. Because the intervention included several components, the study demonstrates the effect of the combined program. Researchers cannot attribute the reduction in rehospitalization to education alone. jamanetwork.com

Together, these studies support teaching practical participation. They also provide a research direction for Patient Better: evaluate a common foundation of navigation skills and test whether patients apply those skills across conditions, providers, and care settings.

### Teaching must include application

Navigation education needs to develop judgment as well as recall. Patients should understand why an activity matters, see how to perform the activity, practice the steps, and receive feedback.

For example, remembering to bring medical records is a starting point. Applying that instruction requires patients to identify the relevant records, obtain them, and make them available for review. A useful evaluation would examine whether patients can complete that process in a situation different from the teaching example. Mayer's distinction between retention and transfer supports assessing whether learners can use knowledge beyond the original lesson. www.tandfonline.com

Patient Better's guiding principles connect this educational approach to participation. Principles 2 and 8 establish preparation and navigation education as foundations for participation. Principle 6 distinguishes educational purposes. Principle 10 directs educators to match teaching methods to the learner. Providers can apply these principles by selecting instruction that addresses an assessed need and giving patients a realistic opportunity to practice.

### Measurement connects education with care

The Patient Better Project Inc.'s assessment framework allows providers to document a starting point and evaluate what happens after an intervention. Patient Better LLC's Academy provides one educational option. Providers may use their own instruction or another appropriate program.

Evaluation should connect the identified need with the skill taught and its later use. The following scenarios illustrate that process; they describe proposed applications rather than demonstrated Patient Better outcomes.

| Identified participation need | Educational response | Evidence of application | Outcome researchers could study |
|---|---|---|---|
| A patient has difficulty organizing information from several specialists. | Teach a consistent method for updating records and preparing a concise care summary. | The patient retrieves relevant information and uses the summary at a later appointment. | Information availability and resolution of discrepancies. |
| A patient is preparing for recovery after a procedure. | Teach how to organize instructions, record questions, track requested information, and contact the care team. | The patient explains follow-up responsibilities and reports concerns through the agreed route. | Follow-through, communication, and unplanned care use. |
| A patient encounters an unfamiliar digital service. | Teach how to identify the task, locate information, request help, and use an alternative route when necessary. | The patient obtains the needed information or secures appropriate assistance. | Completion of care-related tasks and unresolved access problems. |

The Completion Survey can document reported learning and patients' examples of applying the instruction. Demonstrations and follow-up observations can establish whether patients use the relevant skills. Comparative studies can then examine whether the education caused improvements and whether those improvements affected care.

Education addresses skills that patients have not yet learned. Providers must also respond when cost, transportation, illness, inaccessible technology, or unavailable services prevent participation. Measuring these circumstances alongside learning helps providers select the support the patient actually needs.

Navigation education gives patients a foundation for carrying out responsibilities that recur throughout care. Reportable measurement allows providers to examine whether that foundation develops, whether patients use it in new situations, and whether additional instruction or assistance is needed.

## 8 Determining which activities matter most

Providers need to identify what patients must do to carry out their care plans and where patients need help. A patient preparing for an appointment may need to organize symptoms and questions. A patient leaving the hospital may need to clarify medication changes and arrange follow-up care. A patient receiving care from several specialists may need help gathering information and communicating updates. The immediate priority depends on the responsibilities involved and the consequences of leaving a participation need unaddressed.

The connection to care should be clear. If a patient cannot explain a recent change in symptoms, the provider may lack information needed to evaluate the concern. If the patient leaves without understanding the next step, follow-up may remain incomplete. Identifying the activity gives the provider something specific to assess. Identifying the difficulty gives the provider a reason to select education or assistance.

Providers can begin with three questions: What does this care plan require the patient to do? Which activities can the patient carry out with the support available? Which unresolved difficulty needs attention first? This process connects participation assessment to the patient's actual care responsibilities.

## Four activities provide a starting point

The Patient Better Project Inc.'s framework identifies four practical activities for initial investigation. These activities connect preparation, communication, information organization, and follow-through with tasks that providers and researchers can examine. Their importance relative to one another remains a research question.

| Participation activity | Why the activity matters | How providers or researchers can assess the activity | Outcome to examine |
|---|---|---|---|
| Communicate the main concern and meaningful changes. | Providers need a clear account of what prompted the visit and what has changed. | Ask the patient to describe the concern. Assess whether the account includes relevant timing, changes, and effects on daily life. | Whether the provider receives needed information and addresses the concern. |
| Make relevant medication and care information available. | The care team needs current information when reviewing treatment and coordinating services. | Ask the patient to retrieve a medication list or a relevant record. Record accuracy, missing information, and assistance needed. | Whether information is available when needed and discrepancies are resolved. |
| Understand and retain agreed next steps. | Patients need to know what action to take, when to act, and whom to contact. | Ask the patient to explain the next steps and show where instructions are recorded. Clarify whether the steps are feasible. | Whether the patient understands the plan and can begin the required actions. |
| Carry out agreed steps and report obstacles or changes. | Providers need to know whether care is proceeding as planned or requires adjustment. | Review a relevant action or communication, such as arranging follow-up or reporting difficulty obtaining medication. | Whether the next step is completed or the care team addresses the obstacle and revises the plan. |

These activities work together. A patient may retrieve a record but need help identifying what to discuss. Another patient may understand the instructions but lack a workable way to contact the care team. Assessing each activity helps providers locate the difficulty rather than treating participation as a single judgment about the patient.

## Priorities follow the care plan

Providers should give early attention to activities whose absence could delay needed care, create a safety concern, or prevent the next step. The priority may change as care progresses. Before a procedure, the patient may need to understand preparation instructions. During recovery, tracking requested information and reporting concerns may become more important.

A participation gap also needs to be understood before a response is selected. A patient who cannot find a record may need instruction in record retrieval. A patient who has requested the record but has not received it may need help from the organization holding the information. The same incomplete task can reflect different needs.

The Healthcare Proficiency Challenge and Readiness Assessment provide starting information for these decisions. Providers can review relevant responses and ask follow-up questions tied to the planned care. A broad score should not obscure a specific difficulty that matters for the next step.

### Research determines which improvements produce the greatest benefit

Selecting a priority for one patient differs from establishing which activities matter most across patients and settings. Researchers need to test whether strengthening a particular activity produces a useful change in care.

For example, researchers could examine whether teaching patients to prepare a concise symptom account improves the information available during appointments. A separate study could test whether teaching patients to record and explain next steps improves follow-through. Each study should identify the activity being taught, confirm whether that activity improves, and measure the intended care outcome.

Researchers should assess participation before the outcome occurs and account for differences in illness, access, prior skills, and assistance. Patients with more support may participate more effectively and also experience better outcomes. Comparing outcomes without considering those differences could overstate the contribution of the participation activity.

Comparative studies can help identify which educational components make a difference. Researchers might compare a basic preparation lesson with the same lesson plus guided practice. They could then examine whether the added practice improves communication during an actual appointment. Studies can also test whether patients benefit more when education is paired with a change in professional support, such as a clear process for responding to reported concerns.

### Useful priorities balance benefit and effort

An activity deserves priority when improvement offers a meaningful benefit relative to the effort required from patients, caregivers, and professionals. Researchers should examine time, difficulty, accessibility, and the assistance needed alongside care outcomes. Requiring extensive documentation may add work without supplying information the provider needs.

The aim is to identify the activities that help patients and professionals complete care successfully. Assessment reveals where participation needs attention. Education and assistance address the identified difficulty. Follow-up establishes whether the activity improved and whether that improvement mattered to care.

## 9 Does participation change over time

Patient participation needs to be assessed over time because patients learn, care responsibilities change, and available support can change. A patient may learn to organize records during one course of treatment and use that skill with a new specialist. The same patient may later need assistance because illness, a new technology, or the loss of a caregiver makes the task more difficult. Providers need to understand both the change in participation and the reason for that change.

Research on activation supports examining development over time. Hibbard and colleagues found that increases in patient activation were associated with improvements in several self-management behaviors. Activation also increased in the comparison group, which made the effect of the intervention less clear. The study supports following patients over time while showing why improvement after education does not, by itself, prove that education caused the improvement. [12]

### Follow learning through to use

The Patient Better Project Inc. proposes following participation from the initial assessment through education and later care. Providers first document reported practices and circumstances. After an intervention, providers examine reported learning and relevant task performance. Further assessment follows an opportunity to use the skill in actual care.

A patient learning to retrieve medical information, for example, might first practice locating a record. At a later appointment, the provider can examine whether the patient obtained the relevant information and made it available for review. A subsequent task involving a different organization can help researchers determine whether the patient can apply the same process in a new setting.

Researchers should select follow-up timing around the activity being studied. An appointment-preparation skill can be assessed at the next visit. Referral coordination requires enough time for a referral to be requested and arranged. Follow-up at three or six months may help examine continued use when those intervals fit the care pathway. These are study planning options rather than established assessment requirements.

### Record what changed around the patient

Each follow-up should record relevant encounters, new responsibilities, assistance, and changes in access. A patient who now completes a task with caregiver help may have gained effective support without gaining independent ability. Both findings matter, but they answer different questions. Providers should document the assistance that makes participation possible.

Researchers must also distinguish an activity that was not needed from an activity that was not completed. A patient without a referral has had no opportunity to demonstrate referral follow-through. Missing information, an unavailable service, and an unsuccessful attempt should each be recorded distinctly so that providers can select the appropriate response.

### Interpret change in relation to care

The Completion Survey records patients' views of their learning and progress. Education may also change how patients judge their earlier abilities. Researchers should identify whether the earlier ratings were recorded before instruction or recalled afterward and compare reported change with other evidence when available. Retrospective ratings can add insight, but they remain affected by recall and changes in self-evaluation. [26]

A useful change should have a clear practical meaning. Retrieving a needed record, explaining the next step accurately, or obtaining help with an obstacle can matter more than a small change in a total score. Researchers need to establish how much score movement exceeds ordinary measurement error and whether that movement corresponds to an improvement patients and providers recognize. [10]

Repeated assessment gives providers a way to revisit support as care evolves. The research question extends beyond whether patients learn: do patients retain the skill, apply it in another situation, and obtain assistance when the demands of care exceed their current abilities?

## 10 What happens to care communication healthcare use and patient experience

Improved participation matters when patients and professionals can use the improvement to carry out care more effectively. A clearer symptom account may help a provider understand a concern. Organized records may

help the care team resolve conflicting information. A patient who recognizes and reports an obstacle gives the team an opportunity to adjust the plan. Researchers need to examine whether these practical improvements lead to better care and experiences.

The sequence begins with a defined activity. Education or assistance may improve that activity. The improvement may then change the care process and contribute to a later outcome. Each connection needs evidence because outcomes also depend on clinical decisions, treatment effectiveness, access to services, and the patient's condition.

### Measure the immediate contribution to care

Communication measures should examine whether patients convey relevant information and whether providers respond to the concerns raised. Researchers can also assess whether patients understand the agreed next steps. These findings show what happened in the interaction before a study considers more distant outcomes.

Grant and colleagues' Visit Planner trial illustrates this distinction. Patients reported better preparation and communication of priorities, but the intervention did not produce greater improvement in clinical care gaps over six months. A study can demonstrate a useful change in participation while leaving the effect on clinical outcomes unresolved. [11]

Care-process measures can include the availability of needed records, resolution of medication discrepancies, completion of referrals, and timely responses to reported concerns. Researchers should define each outcome before collecting data and identify the source used to confirm the result. A care plan appropriately revised after a patient reports a problem should be recognized as a response to new information.

### Examine healthcare use in context

Trials of supported discharge and care transitions provide evidence that combined programs can change subsequent healthcare use. Coleman and colleagues found lower rehospitalization at 30 and 90 days among older adults receiving transition tools and coaching. Jack and colleagues' randomized trial found lower combined emergency department and hospital use within 30 days after a program that included discharge preparation and follow-up. These studies support evaluating education together with practical support. They do not isolate the effect of one participation skill. [13,14]

Lower use of services is not automatically a better outcome. A patient who learns to report a concern promptly may appropriately need another appointment. A patient who avoids necessary care may have fewer visits without experiencing better health. Researchers should examine the type and timing of care, the reason for contact, and related health outcomes.

Cost evaluation should include the resources required to deliver education and assistance. Patient and caregiver time also matters. Claims of savings require a comparison of relevant costs and outcomes rather than a count of avoided encounters alone.

### Include the patient and professional experience

Patients should be asked whether they understood their responsibilities, could obtain help, and felt that professionals addressed their concerns. Evaluation should also examine effort, frustration, and whether the education made care easier to manage. A completed form or course cannot answer those questions by itself.

Professionals can report whether patient information was usable, whether support needs became clearer, and how much time the process required. Researchers should compare those reports with observable measures where feasible. Preparing patients may change staff work as well as patient behavior, and both effects belong in the evaluation.

### Connect participation with more demanding care plans

Researchers can study participation alongside a specific procedure or treatment pathway. The care team first identifies what patients need to do, such as organize instructions, track requested information, or communicate concerns during recovery. The study then examines whether assessment and support improve those activities and whether the changes relate to outcomes.

These studies could help providers determine which preparation is useful for particular care demands. The Patient Better Project Inc.'s assessments are not yet established predictors of procedural success, complications, or emergency care. Their proposed role is to identify support needs and create a documented basis for testing those relationships. Participation scores should guide investigation and support rather than serve as an untested gate to treatment.

## 11 One measurement framework with different interventions

Providers need room to improve patient participation using methods suited to their patients and practices. A common assessment framework can support that work by defining what is measured and how results are recorded. The intervention can vary while researchers preserve a clear account of the participation activities under study.

The Patient Better Project Inc. is the nonprofit responsible for developing and licensing the participation assessment framework. Patient Better LLC provides the Academy and associated educational resources as an intervention option. Providers may use their own education or another appropriate source of support within the applicable research and licensing arrangements. Assessment does not depend on Academy enrollment.

### Keep the assessment clear while allowing different teaching approaches

Researchers should document the assessment version, questions, scoring rules, administration method, assistance, and timing. They should also define the population and care responsibilities being studied. These details establish what the results represent and allow other researchers to evaluate the comparison.

Teaching can vary in content, format, duration, and delivery. A physician may provide a brief preparation lesson. A nurse may lead a communication exercise. A practice may offer structured navigation education with guided practice. Researchers should describe what patients actually received, including changes made during delivery. The TIDieR reporting guide provides a practical structure for documenting interventions so that others can understand and reproduce them. [15]

A tool used to teach a skill is part of the intervention. For example, the Appointment Companion can help patients organize concerns and next steps. Researchers can examine its use, but completing the companion alone should not define success. A stronger evaluation examines whether patients communicate relevant information or carry out the agreed next step.

### Use the Completion Survey across appropriate interventions

The Completion Survey can support evaluation of provider-developed education as well as the Academy when its questions match the learning being studied. Researchers should document how they handle program names and questions about specific resources that another intervention does not teach. Each adaptation needs a version identifier and a clear explanation of what changed.

For comparisons between interventions, researchers should identify a shared set of relevant questions and practical outcomes. Program-specific feedback can be collected separately. Changes to a measurement question are changes to the assessment, even when the intervention is the reason for the change. Evidence is needed before scores from different versions or populations are treated as equivalent.

### Compare approaches against the same care responsibility

A practice could compare its usual preparation instructions with a structured lesson and guided practice. Both groups could complete the same relevant assessment and be evaluated on communicating concerns at the next appointment. A later study could compare several educational approaches if the sample size and resources support that design.

Researchers should examine who benefits, which needs remain, and how much effort each approach requires. Findings may support a shorter lesson for one need and more extensive education for another. A shared framework gives providers a way to improve their methods while contributing evidence that other practices can examine.

## 12 A staged research program

The Patient Better Project Inc. has developed assessment tools and a practical participation framework. The next task is to test how well the tools identify needs, how education changes participation, and whether providers can use the findings to improve support and care. The following stages describe a proposed research program, not completed studies.

Researchers should use findings from each stage to refine the next. Some activities can proceed together, while others depend on resolving an earlier measurement question. The Medical Research Council framework supports this approach by connecting development, feasibility, evaluation, and implementation with attention to context and how an intervention is expected to work. [16]

### Stage 1 Confirm the activities and questions

Researchers should map each assessment question to a defined participation activity or circumstance. Clinicians, patients, caregivers, and measurement specialists should examine whether important responsibilities are missing and whether each question is understandable. Patients should explain how they interpret the wording and choose an answer.

This work tests the existing framework against actual care experiences. Participants should include people with different care demands, languages, access needs, and assistance arrangements. Researchers should include people who do not enroll in education so that the tools are not developed only around willing course participants.

The output is a documented activity map, a record of any revisions, and a clearly identified research version of each instrument. Administration instructions should explain how to record assistance, activities that were not needed, and missing responses.

### Stage 2 Test usability and measurement quality

An initial practice study should examine completion time, unanswered questions, staff workload, and whether providers can identify a specific support need. Researchers should determine whether the process reaches patients who need assistance and whether follow-up is workable.

Measurement studies should then examine consistency, accuracy of interpretation, and the usefulness of the proposed score bands. Relevant self-reports should be compared with demonstrated tasks and suitable established instruments. Researchers should test whether the Completion Survey captures reported change in a way that patients and providers can interpret. COSMIN guidance can inform the design of these measurement studies. [10]

A measurement specialist should determine the sample size needed for each analysis. The calculation should reflect the questions, expected responses, and precision required. A single participant target cannot serve every validation and intervention study. The output is evidence identifying which questions, scores, and interpretations are ready for further testing.

### Stage 3 Follow learning and practical use

Researchers should collect a baseline, document the education or assistance provided, and assess patients after an opportunity to use the skill. Studies should record both the Completion Survey responses and relevant evidence of application. Testing a familiar task and a different task can help distinguish practice with one example from learning that transfers across care.

A small comparative study can test recruitment, group assignment, follow-up, and outcome collection before a larger trial. Patients who discontinue education should remain eligible for follow-up where they consent. Researchers need to understand both completion and noncompletion to judge whether the approach is workable.

The output is a tested study process and a justified choice of the main outcome for a larger trial. A feasibility study establishes whether the work can be carried out; the size and design may still be insufficient to establish effectiveness.

### Stage 4 Test intervention effects and activity priorities

A comparative trial should examine a defined intervention against a clearly described alternative, such as usual preparation instructions. Random assignment can help separate intervention effects from preexisting differences. Assigning whole practices or clinicians may be appropriate when changes in staff behavior would otherwise affect both groups.

Researchers should identify the main outcome and analysis plan before examining the results. The study should account for differences in starting ability, illness, access, and support. Researchers should report uncertainty and examine whether patients lost to follow-up differ from those who remain.

Further studies can test individual teaching components or combinations of support. Researchers can investigate whether changes in participation help explain changes in care, but an association between those

changes is not enough to establish the pathway. Findings showing little benefit or unexpected difficulty should guide revision as clearly as favorable findings.

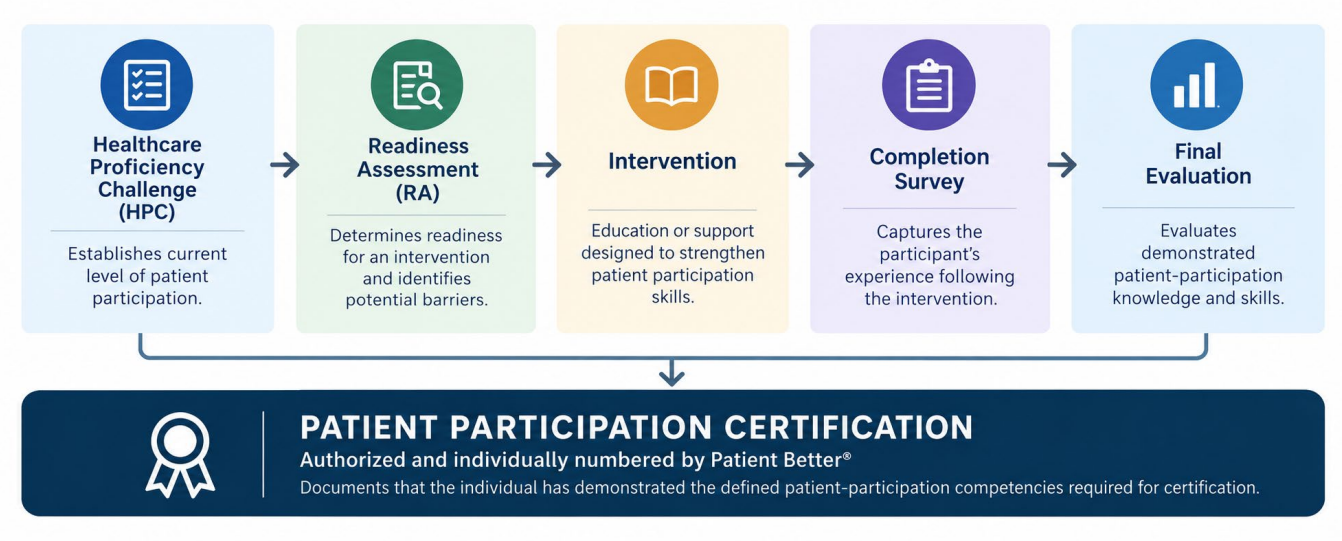
### Stage 5 Test transfer and use in other settings

Independent teams should examine whether the supported approach works in other practices and populations. Research should test whether patients apply foundational navigation skills when diagnoses, professionals, or technologies change. New languages and caregiver-reported versions require evaluation rather than an assumption that the original interpretation will hold.

Implementation studies should examine reach, staff effort, patient burden, cost, and continued use. Researchers should ask whether assessment changes the support offered and whether patients with greater needs can access that support. Use in health-plan reporting or payment decisions would require evidence appropriate to those purposes.

Progress through these stages would establish a stronger basis for professional use: an understandable assessment, dependable interpretation, effective education or assistance, and evidence that the process improves care under defined conditions.

**Figure 1. How Patient Participation Is Assessed, Supported, and Evaluated.**




## 13 Research governance and collaboration

The Patient Better Project Inc. welcomes clinicians and researchers who want to test, improve, and apply the participation framework. Collaboration should produce findings that providers can use and other researchers can examine. Physicians may study their own interventions, and participation in research does not require use of Patient Better LLC's Academy.

### Define responsibilities before the study begins

Each collaboration should identify the research question, study population, instruments, intervention, and outcomes. The agreement should also identify who recruits participants, manages data, conducts the analysis, and prepares publications. Licensing terms and permissions to adapt materials should be established before use.

Researchers should preserve the distinction between developing a tool, delivering education, and evaluating results. Jennifer Woodruff's leadership roles in The Patient Better Project Inc. and Patient Better LLC should be disclosed when those tools and educational resources are studied. Reports should identify funding and other interests that readers need to assess the findings. Independent methodological review and analysis can strengthen confidence in the work.

### Make participation and data use clear

Investigators should obtain the appropriate ethics review before recruiting research participants. Study materials should explain what information will be collected, how the information will be used, who will have access, and how long the records will be retained. Education enrollment and research participation should be explained separately.

The supplied forms include identifying information. Researchers should collect only what the study needs and establish secure procedures for linking assessments over time. Research use beyond the purposes described on an existing form needs to be addressed in the study's participant information and data arrangements.

Patients should understand that a reported difficulty is information for support and research. Staff should explain how assistance is recorded and how patients can decline research participation. Study procedures should make room for patients who use interpreters, caregivers, or other support.

### Preserve useful flexibility and accountable reporting

Researchers may propose changes to teaching or assessment materials. Changes should have a stated purpose and be recorded in the relevant version history. Keeping those records allows investigators to improve the framework without obscuring what was tested.

Research agreements should allow publication of favorable, unfavorable, and inconclusive results. Trials should have a public protocol or registration appropriate to the study, with outcomes and planned analyses recorded before results are known. Reports should explain deviations and distinguish planned analyses from later exploration.

The immediate opportunity is to build clinical and measurement partnerships for content review, usability studies, and direct instrument testing. A first collaboration can deliver an activity map, a research version of the tools, administration guidance, and a protocol for evaluating learning and application. Those deliverables create a practical starting point for broader studies across interventions.

## 14 What this framework makes possible

The Patient Better Project Inc. makes practical patient participation an explicit subject of assessment, education, documentation, and reporting. Providers can identify a care responsibility, examine the patient's starting point, select support, and revisit whether the patient can carry out the activity. This sequence connects participation with a decision providers need to make: what will help this patient take the next step in care?

The nine questions guiding this paper lead to a connected research agenda.

### Can participation be measured and strengthened

Defined questions and consistent procedures make participation responses recordable and reportable. Studies must establish the reliability and accuracy of The Patient Better Project Inc.'s instruments and the usefulness of their interpretations. The Healthcare Proficiency Challenge, Readiness Assessment, and Completion Survey contribute different information and should retain those distinctions in reporting.

Published trials support teaching practical preparation, communication, and self-management skills. Patient Better organizes navigation education around responsibilities that recur across care. The Academy is one intervention option. Providers can also evaluate their own approaches. Direct studies must establish how well each approach works and whether patients use the learning in practice. [11,13,17,23–25]

### Which activities matter and whether change lasts

The immediate priority follows the patient's care plan and the support needed to complete the next step. Research can determine which activities produce the greatest benefit across patients and settings. Repeated assessment can examine retention, transfer, and changes in assistance as care demands evolve.

Researchers should measure participation and care outcomes separately. Clearer communication, more usable information, and better follow-through are practical outcomes worth examining. Effects on health, emergency care, costs, and patient experience require direct evidence rather than an assumption that a higher participation score guarantees a better outcome.

### What patients need and where support falls short

Patients need clear responsibilities and preparation for carrying them out. The central gap arises when professionals provide information or invite involvement without determining whether patients can apply the guidance. Navigation education addresses practical skills, while other assistance addresses circumstances that instruction alone cannot change.

Health literacy, activation, and engagement provide foundations for understanding these needs. Practical participation connects those concepts with specific activities that can be discussed, assessed, and supported. Comparative research should establish what additional information the participation framework provides and whether that information improves professional decisions.

### Why a defined category matters

A defined category gives providers a consistent way to name the activity, record the need, and examine the response to support. Patients gain a clearer account of their role and opportunities to learn the skills that role requires. Researchers gain a structure for testing which interventions help and under what conditions.

The proposed contribution is a common foundation for participation across the healthcare journey. As care introduces new responsibilities, providers need evidence about whether patients are prepared and what assistance will help. The Patient Better Project Inc. has developed the starting framework. Collaborative research can establish its dependable uses and improve the tools as evidence develops.

## Appendix A Internal sources and version notes

A1. Patient Better Project Patient Participation Reference Paper. Supplied working paper dated 24 September 2026. Source for the original framework, organizational roles, and proposed research stages. Descriptions of intended benefit are not treated as completed study findings.

A2. Healthcare Proficiency Challenge. Supplied DOCX snapshot containing ten questions and four affirmative-response bands: 0–2, 3–4, 5–6, and 7–10. Research should identify the exact version administered and retain the item responses alongside any score.

A3. Readiness Assessment License. Supplied DOCX snapshot with five numbered sections and a question about anticipated living changes over six months. Later versions should be documented separately before results are combined.

A4. Patient Empowerment Waiver. Supplied PDF. Used to distinguish documentation of a participation or support decision from measurement of proficiency. The paper does not evaluate the form's legal effect.

A5. Completion Survey. Supplied DOCX, including the copy provided on 25 September 2026. Contains 18 paired five-point ratings in three groupings and written feedback questions. The form alone does not establish when the earlier ratings were collected. References to the Patient Better Program, SOAP Note, and Treatment Plan Calculator require attention when adapting the survey for another intervention.

A6. The Appointment Companion. Supplied PDF. Source for preparation and follow-through prompts. When used to teach or support participation, the companion is an intervention component whose use should be distinguished from independent evidence of improvement.

A7. Patient Better Appointment Participation Methodology. Supplied working document. Source for practical activities across the appointment sequence and the connection between patient contributions and professional support.

A8. Patient Better Academy and Starter Kit Master Overview. Supplied DOCX. Source for the scope and intended educational functions of Patient Better LLC's resources. Product descriptions establish what is offered rather than clinical effectiveness.

A9. Patient Better Public MEARS Research Companion. Supplied document dated August 2026. Source for proposed measurement and reporting uses. Commercial, competitive, and policy strategy materials are not treated as scientific evidence of outcomes or regulatory recognition.

A10. The 10 Guiding Principles of Patient Better. Supplied PDF. Source for patient-prepared care, navigation education, educational purpose, participation capacity, and teaching suited to the learner. These principles guide the proposed framework; their application remains subject to research evaluation.

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Source note. This working paper draws on selected journal articles, reviews, and methodological guidance. Sources added during the revision were checked through 25 September 2026. Some findings were assessed through published abstracts. The review is not a systematic review, and the cited external studies do not directly validate Patient Better's assessments or establish the Academy's effectiveness.